



As the founder and president of the International Foundation for Functional Gastrointestinal Disorders, I have had the opportunity to talk intimately to many people about their experiences with fecal incontinence. I want to share with you some of what I have learned about this disorder.

Fecal incontinence is a disorder that is generally associated with the older adult although it is a condition that affects people of all ages. Incontinence affects all age groups – children, young adults, and older adults. However, incontinence may very well occur later in life, but, it is just as likely that the older adult has managed their incontinence for many years. It is important to recognize that for many people incontinence is treatable.

Unfortunately, there has been a lack of information available to the public concerning fecal incontinence and a general lack of awareness of the prevalence of the condition.

Fecal incontinence not only affects the individual, but also the entire family. Family members need to be educated about incontinence as well.

It is not easily talked about – even with a physician. If a physician does not directly ask about incontinence, the chances are that the patient will not offer this information.

What it is like to live with fecal incontinence

Regardless of whether a person is young or old, there are many common factors for people with incontinence. It can lead to isolation. It is not easily talked about. Often, people are reluctant to discuss this with their physician. If a physician does not ask a patient directly, the chances are that the person will not offer this information. It is common to find that a person experiencing urinary incontinence may also be incontinent of stool. Although they will acknowledge the urinary incontinence, they often will not acknowledge the fecal incontinence.

It takes courage for a person to say that they experience incontinence. There is a great deal of stigma associated with this condition. To the person who suffers, saying they have

incontinence may seem more like a confession than a statement of fact. Too often, after summoning the courage to talk about their incontinence, the person is met with disinterest or lack of understanding – a response that only heightens feelings of hopelessness or isolation. It is important that an acknowledgment of incontinence be met with an empathetic and supportive response.

It is of paramount importance that caregivers recognize the psychological impact that incontinence can have on a person's life. Too often, the only concern is for containment of fecal matter with too little attention given to the psychological impact, social considerations, and quality of life for that person.

The uncertainty of living with the ever present possibility of having an episode of incontinence can be disabling. It is often difficult for people who do not have the disorder to understand the true impact.

Most people who experience incontinence feel that much of their life revolves around being in close proximity to a bathroom.

A sense of freedom and of being in control comes with having a bowel management program that works for the individual, and with being prepared for an incontinent episode in a public place. Incontinence in public is generally the greatest fear that people have.

That fear comes from feelings of shame, embarrassment, humiliation, and anger that are generated by an episode of incontinence. It is difficult to control this range of emotion and manage to get to a bathroom, clean up, change clothes, and return to an activity as if nothing happened – while at the same time knowing that it could happen again at any moment. The older adult may also be confronted with not being able to get to the bathroom quickly, being less agile, and perhaps having to rely on someone else to help them. All of this adds to the frustration of coping with incontinence.

Coping with incontinence is dependent on a number of different things. Acceptance and support are primary factors in

how one copes. Adjustments and compromises may have to be made. In order for an individual to accept this disorder, they need to feel assured that the best possible quality of life is still available to them.

The degree of acceptance among different people will vary. Some people feel as if their life is over and give in to the feelings of lack of control. The incontinence is unacceptable and they lack the ability to manage it. They probably do not have a support system that recognizes how difficult incontinence can be. As a result, these people become angry or they may become passive and make little or no attempt to help themselves.

Anger can be constructive for some. It can move a person to take action in a positive way. In fact, it is okay to be angry about this; it is to be expected. Incontinence is a loss and it needs to be recognized as a loss. A person may need some professional help with making this adjustment.

A person with incontinence can no longer just go and do whatever they want to do without giving thought to having access to a bathroom. People may become less active. Mobility may become limited; a person might not want to travel by bus or by airplane, for example. Some people feel as if their entire identity has been changed as a result of their incontinence. They feel controlled by this disorder.

Support for the person with incontinence is of primary importance. People are much more likely to feel empowered and better able to contend with incontinence if they don't feel alone or fearful of expressing themselves.

Family members or caregivers may need to be educated about fecal incontinence so they can be more supportive, not only in physically managing, but in coping with the emotional aspects as well.

Here are some things that care givers and family members can do to help

They can recognize that, in most cases, the person is unable to control this. People with incontinence go to great lengths to hide this and to avoid an embarrassing situation. The energy spent trying to manage this so that other people won't know can be enormous. People become physically and emotionally tired from having to act as if everything is "just fine."

It is important to listen. Many people with incontinence just need an outlet to express their frustration. They need to

be able to work through the levels of grief that are associated with the loss they feel.

People with incontinence should not be made to feel bad about this, shamed or embarrassed even in a joking way. Humor can be uplifting, but only if the person has come to terms with the condition. There is nothing funny about incontinence for the person who lives with it every day.

People with incontinence need to be prepared. It may mean wearing protective undergarments. It helps to have clean up supplies and extra clothes available at all times. Wearing a protective undergarment is difficult to accept. People will avoid wearing them as long as possible. There is a sense of denial that exists with incontinence. Wearing a protective undergarment means acknowledging, and no longer denying, the incontinence.

Reassurance of access to restroom facilities is important. The first thing to do, when somewhere outside the home, is to identify where the restroom is and assure easy access.

It is important to be flexible. Plans may need to be changed at the last minute. If the person with incontinence does not feel comfortable leaving home, they should not be forced to do so. Tomorrow may well be a better day.

Medical professionals can offer support

It is imperative that those unable to care for themselves are treated with dignity. Listen to what the needs of the individual are. Give them as much information on the subject as possible. Additional education materials are available through the International Foundation for Functional Gastrointestinal Disorders and other organizations.

It is important that you help the person with incontinence maintain an attitude of self confidence and self respect.

Remember, incontinence is a personal struggle. You can become an important ally. If you find yourself saying, "This is something you will just have to learn to live with," then please offer that person information on *how* to live with it.

Regaining Control

By: Linda Pribek, WI

(Author's Note – Each of us living with bowel dysfunction must deal with situations in our own way. By sharing a personal account of living and dealing with fecal incontinence, I hope others may find new ways of accepting the daily challenges presented by bowel dysfunction.)

Warm summer days at the beach...holidays spent with family and friends...sunrise over the lake as you cast your line into the water...a weekend sightseeing trip with old friends...these and many other events can fill us with warm, happy memories or stir us with anticipation, as we plan and prepare. For those of us living with bowel dysfunction, another emotion is too often present – *FEAR!* Living with that fear changed me from an extremely active person with many interests to a prisoner in my own home. As I became increasingly afraid of venturing far from my bathroom, incontinence continued to rob me of many meaningful experiences. Slowly, with the love and support of my family, physicians, and friends, I began regaining the control over my life that bowel dysfunction (in my case, incontinence) had taken from me. Many difficulties are still present for me, and I deal with incontinence on a daily basis. But, when I started looking for ways of managing my bowel dysfunction, I gained confidence in my ability to take control of the situation. As I allowed myself the freedom to take risks, and the freedom to make mistakes along the way, I saw my life becoming fuller and happier once again.

The first step in venturing outside of my home, and regaining control of my life, consisted of keeping a journal. In my journal I recorded my daily foods (what, how much, and when I ate or drank), along with my daily bowel pattern. Since each individual may react differently to various foods, I used my journal to develop information specifically related to my body. This approach allowed me to develop a list of “safe” foods for managing my personal situation. Having this information gave me the freedom to eat out, or leave home, without constant fear of being embarrassed by incontinence. I save any experiences with new food for times when I will be at home and add these foods to my list for future reference.

The second step involved being prepared should an accident occur away from home. This preparation involved putting together items I find necessary or helpful into my “survival kit.” (Note: the following items are specific to my

situation. You may want to consider variations to suit your own personal needs.)

Carry Case. Choose something you are comfortable with. Some suggestions are: camcorder/computer bag, briefcase, large purse, carry-on, sports bag, small duffel bag, back-pack. Whatever you select, be sure it is lightweight, has adequate space for your needs, and has several compartments.

Medication. *Use of medication should be as directed by your physician.* If you require several different medications, it will save space to use a small pill case with compartments. The case I use will hold a one-week supply of medication.

Lubricant. You will need to find the lubricant best suited to your situation. If you have questions it is advisable to consult your physician, pharmacist, or nurse. To save space, carry a partially used tube or travel size.

Gloves. Purchasing gloves that are the correct size for you is important. If your gloves are too large, they will be clumsy and interfere with efficient cleaning or bowel management. If too small, gloves will restrict finger movement during bowel management and may tear during clean up.

Finger Cots. Unlike gloves, these do not provide complete protection. However, they are smaller, fit easily into a wallet or small purse, and work well if digital stimulation or suppository insertion is required.

Protective Undergarment. Experiment with available items that are designed mainly for urinary incontinence, until you find one you feel comfortable wearing. Personal preference and comfort should be your main considerations.

Tissue. Any type may be carried. To save space, place several single sheets in your carry case rather than an entire box.

Cleansing Wipe. I prefer a pre-moistened, alcohol free baby wipe. I carry the 16 count 7.6” x 7.5” size, in a hard carry case. This gives me a compact size, with a wipe large enough to provide good cleansing. The hard case, with small quantity, helps keep moisture in the wipes until used. If wipes become dry they can be moistened with water, however, they do not give the same “fresh” cleansing. If you use a large number of wipes it may be cheaper to buy in larger quantities and refill your case from that supply.

Chux/Disposable Underpad. This is a waterproof, highly absorbent, disposable sheet. I prefer the 22.5” x 33.5” size for larger work space. This item is very helpful if you cannot use a restroom to clean up (or when beginning your bowel management program). It protects carpets or other areas from being soiled during cleansing.

Plastic Bags with Fasteners. I carry a few different size plastic bags that can be used to seal soiled garments until I get home. I also use the bags for disposal of soiled items. Your state or community environmental programs may have requirements or suggestions for disposing of your medical waste. You should contact them for any information you may need.

Change of Outerwear. Pants, slacks, skirt, or shorts should be a neutral color that can be worn with many items. Choose a lightweight material that folds to compact size and is wrinkle resistant. Sports or workout clothes are ideal. Make your selection something you are comfortable wearing, since you may be very self-conscious at the time you need to change your clothes.

Deodorizing Spray. Do NOT substitute perfume for this item. Choose a product that eliminates fetid odors, rather than trying to cover up the odor with a heavy perfume, which will generally result in an even stronger offensive odor. You may want to check with your local hospital, clinic, or pharmacy for products in your area. Test the product at home to see if it works for your situation. Keep in mind that you will want a small carry size.

Drinking Water. If I am going to be away from home for a long period of time I often carry a sports bottle with water or other liquids. Another suggestion would be to use only bottled water or liquids you have tested previously. Refer to your personal journal for items that may increase your chance of developing gas or diarrhea.

Food. Depending on the activity I am attending, I may bring small food items, like fruit or crackers. I have found this helpful when attending events that serve only foods that are generally a problem for me. I also find that eating only small amounts throughout the day will help me avoid the natural active reflexes and peristalsis (wave-like movement) of my bowel, after a meal.

I keep my "survival kit" packed at all times. In appropriate weather I just leave it in my car. If any item is used during the day, I simply replace it when I get home. I would like to be able to say that I have never had to make use of any of these items but, unfortunately, living with bowel dysfunction means facing the fact that accidents DO happen. I can say that, with the help of caring friends and family, I have found that it is possible to regain control and manage the challenges of living with bowel dysfunction.

There are resources available to help locate items that may allow you to regain control over your personal situation. In addition to IFFGD, a few suggestions are: your physician, clinic, nurse, pharmacist, and support groups. If you are

embarrassed discussing this subject in person, try using the telephone to obtain information regarding items you have questions about or cannot locate. Once you start dealing with your situation, you will find it becomes easier to talk about and live with. Whatever means you choose to use with your personal situation, I wish you success. Keep in mind that, while bowel dysfunction may present daily challenges or obstacles to deal with, it does not have to rob you of a full and active life.

About IFFGD

The International Foundation for Gastrointestinal Disorders (IFFGD) is a 501(c)(3) nonprofit education and research organization. We work to promote awareness, scientific advancement, and improved care for people affected by chronic digestive conditions. Our mission is to inform, assist, and support people affected by gastrointestinal disorders. Founded in 1991, we rely on donors to carry out our mission. Visit our website at: www.iffgd.org or www.aboutIncontinence.org.

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